



ucare

## **The Caregiver Guide**

### **Module 10**

## **Community Supports for Remaining at Home**

**Participant Booklet**

# Module 10

## Community Supports for Remaining at Home

### PURPOSE

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Module 10 is designed to teach caregivers how to support a family member to remain at home despite failing health or to return home after an illness or injury. It will teach you how to obtain help with daily, weekly or monthly tasks. These tasks may include personal care for your family member, household chores, or other necessary tasks for maintaining your family member at home. Information will be included about where to apply for and locate services and/or funding to help pay for support services.

### WHAT YOU WILL LEARN

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After completing this module, participants will be able to:

1. Identify areas where you need help and create a checklist.
2. Identify sources for getting volunteer help with tasks on your checklist.
3. Describe the types of services that you need that are available from public programs.
4. Identify where and how to get services and/or funding to help pay for in-home and community support services.

**This module will not cover technical questions about eligibility for public programs such as Medicare, Medicaid, Alternatives or Caregiver Support programs. These questions will need to be answered by an eligibility specialist for the particular program.**

## INTRODUCTION

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This module will help you learn ways to support your family member to return home after an illness or injury, or to remain at home despite failing health. You may need help with daily, weekly or monthly tasks. These tasks may include personal care for your family member, household chores, or other necessary tasks for maintaining a home. You may need relief at times from your caregiving role. These supports are necessary if you are to maintain a stable home for your family member.

This module will help caregivers identify the areas where you need help and recommend how to get it. Each person's needs are unique and complex, so there can be no single program that is likely to provide all that you need. So we will begin with a process of helping you to assess your situation. Then we will provide information about where and how to get help.

### **Here are some examples of caregiver situations:**

Nancy is a small woman who lives with her 6'5" father with multiple sclerosis. He is no longer able to bathe himself. Nancy is afraid that he will fall in the shower.

Merle is a caregiver for his spouse Carol, who has diabetes. She is no longer able to check her own blood sugar and prepare her insulin due to a visual impairment. And, Merle needs help planning healthy meals for her.

Carla cares for her brother who has AIDS. He is unable to maintain his home and yard and the neighbors are complaining that his lawn is overgrown and unsightly.

## ASSESS YOUR SITUATION

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Think about the tasks that must be performed daily, weekly and monthly to maintain your family member at home. Then complete the Checklist on page 4.

- Check tasks that your family member is unable to perform by him/herself
- Check tasks that the caregiver is unable to perform or finds difficult to perform

If there are needs that you and your family member have that are not on the list, write them in the blank spaces on the checklist. Once you have completed the checklist you are ready for the next step.

Notes:

# Chart A: Checklist of Needs

Home Health			Personal Care			✓
Medication reminder		Wound care		Bathing		Dressing
Tube feeding		Chemotherapy		Grooming		Toileting
Catheter		Dialysis		Eating		Transferring
Check blood sugar		Transfusions		Making self understood		Ability to understand
Insulin injections		Ostomy care		Answer phone		Make phone calls
Medical transportation		Tracheostomy		Meal prep		Housekeeping
Medical equipment		Medical supplies		Shopping/errands		Transportation
Physical therapy		Occupational therapy		Exercise / Getting out		
Homemaking			Chore Service			
Vacuum		Change linens		Wash walls		Shampoo carpets
Banking		Laundry		Clean windows		Move furniture
Pay bills				Yard work		
Respite						
In home companion		Adult Day Care				
Overnight out-of-home						

## FINDING HELP FOR TASKS ON YOUR CHECKLIST

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### Where to get help?

- Family
- Friends
- Neighbors
- Churches
- Neighborhood groups
- Call 211 or go to [www.UCare.utah.gov](http://www.UCare.utah.gov)

Begin a conversation by showing your checklist to your family and friends. They may want to help.

To begin, start with your family, friends, and groups of which you are a member, such as a church or other neighborhood groups. You should explore the willingness of those closest to you to assist you and your family member before going to public agencies. Why? Because they may want to help. They want to support you in the goal of helping your family member remain at home. Perhaps you have never asked for help because you didn't want to be a burden on others. You may find that people are very willing to help you in small or large ways that you did not expect. They may not know what you need. So you need to ask.

One way to begin a conversation would be to show your completed "Checklist of Needs." This provides a nice way for them to pick tasks that they like to do and you get the help you need. It becomes a real win-win for everyone involved. You get help. Your helpers get satisfaction from helping.

If your family and friends are doing all they can, you need to branch out beyond your inner circle and contact community organizations that can help. Which ones you contact will depend on the kinds of help you need. For example, someone from your church may be able to provide respite

once a week so that you can go grocery shopping. Perhaps the neighborhood scouts could help with spring or fall yard cleanup. Your neighbor may be willing to launder your sheets and towels when she does her own.

If none of these strategies gets you the help you need, or if there are still things on your list that you can't get help for, you can look for agencies that have programs for specific kinds of services. Maybe some of the things on your list require special skills. There are pros and cons of using agency services.

## ADVANTAGES OF USING AGENCY SERVICES

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- Provide you with a needed break
- Relieve you of tasks that you are not comfortable doing, or tasks you don't know how to do
- Prevent or postpone institutionalization for your family member
- Possibly relieve your family member of feeling like a burden

## RELUCTANCE TO USE AGENCY SERVICES

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- Caregivers may feel like they are not doing their duty
- Don't want to use government services
- Privacy concerns
- Bureaucratic hassles
- Don't know what services are offered

If you make the decision to request assistance from an agency, your family member will have to meet the qualifications set by the agency or funding source.

Refer to your checklist. There are different resources available depending on what you need. Agency funding is

usually tied to different types of needs. It's helpful to understand four categories of services.

## CATEGORIES OF IN-HOME SERVICES

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- Home health
- Personal care
- Homemaker/Chore services
- Respite care

Look on page 10 for the chart titled “Guide to In-Home Supports.” The chart is a summary of the information described below. As you work with agencies you may find that some terms are not familiar. The Glossary on page 26-27 will help you better understand their terms.



### **1. Home health**

Home health services are typically approved by a physician and supervised by a health professional such as a nurse. The services are provided in a person's home by a licensed health professional who is qualified to perform the tasks needed by the patient. The home health professional may oversee wound care, transfusions, chemotherapy or ostomy care. A Registered Nurse may administer wound care or replace catheters. Licensed therapists, such as a physical or occupational therapist may supervise therapies in the home. A certified nursing assistant (CNA) may provide hands-on assistance such as bathing or dressing, or stand-by assistance such as reminding a patient to take their own medications.

### **2. Personal care services**

Personal care services (also called personal attendant, personal assistance services, or PAS) can help with “activities of daily living” (ADL), such as bathing, toileting, getting



dressed, or eating. PAS may also provide help with “instrumental activities of daily living” (IADL), such as meal preparation, shopping and housekeeping. You may be able to hire a friend, neighbor or another family member to do these things for the person in need. You are not permitted to hire the spouse of the Medicaid recipient with Medicaid funds. You can locate personal attendants through a home health agency.

Some PAS services are “participant-directed” which means that the individual has control over the hiring, supervision and retention of the personal attendant, including approval of the attendant’s time sheet. If the person is unable to direct his or her own personal attendant, another person may be appointed to help in the supervision. [Refer to Module 11 for more information about hiring a personal attendant.]

Another service category called “companion services” can be used to support community activity to prevent isolation of the person. Companion services may assist with such tasks as cooking, shopping and getting to appointments for a person who is unable to do these things for themselves. The housekeeping or other supports must be incidental to providing companionship and not the primary purpose of the visit.

### **3. Homemaker / Chore services**

Homemaker services are “light” household activities such as meal preparation, laundry and routine household care. Homemaker services are provided to maintain a clean and sanitary living environment for the individual.



Chore services are “heavier” housework such as washing floors or walls, shoveling snow, or making repairs to make the home safe. These services are provided to help seniors and people with disabilities to remain in their homes. Providers of these services must have a current business license that permits them to provide the services.



#### **4. Respite care**

Respite care services are “relief” for the caregiver. Respite care can be provided in the home to give the caregiver a break from 24/7 responsibility. Respite care may be provided by a companion, a neighbor, or a personal attendant from an agency. As with the home health and personal attendant services, individuals must pass a criminal background check in order to provide these services. Respite may also be provided outside the care receiver’s home, such as an adult day program for a few hours, or a residential care facility overnight or for several days.

#### **5. Hospice**

Hospice services provide special care for individuals who are near the end of their life and for their families either at home, a special facility or a hospital. Hospice provides comfort rather than lifesaving heroic measures. The services address the emotional, social, financial and spiritual needs of individuals who are terminally ill and their families. Services are provided by a hospice team and include comprehensive medical management, comfort care, education and spiritual counseling.

Hospice providers are certified by Medicare and licensed by the state to provide the comprehensive range of services

needed by the individual and family. A physician makes the determination of when hospice services are needed, and the individual and/or a family member choose hospice care.

## Chart B: Guide to In-Home Supports

	What tasks do they help with?	Who can provide?
<b>Home Health Services</b>	Nursing services such as dressing wounds, changing catheters, or therapy services	Licensed health professionals <sup>2</sup>
	Hands-on or stand-by assistance with activities of daily living , such as, bathing, dressing, reminders to take medications	Certified Nursing Assistant (CNA) <sup>2</sup>
<b>Personal Care Services</b>	Personal attendant services are <i>participant-directed</i> help with personal care such as bathing, dressing, cooking, eating.	Friend, family member <sup>1</sup> , home health worker <sup>2</sup>
	Companion services support community activity and prevent social isolation, and can help with cooking, laundry, shopping.	
<b>Home-maker / Chore Services</b>	Homemaker services are “light” household tasks such as, cooking, cleaning, laundry.	Friend, family member <sup>1</sup> , trained homemaker <sup>3</sup>
	Chore services are “heavier” household tasks such as washing floors or walls, yard care, snow removal.	Neighbor, chore service agency <sup>3</sup>
<b>Respite Care Services</b>	In home relief for caregiver	Family member <sup>1</sup> , friend <sup>2</sup>
	Out of home stay	Licensed facility
<b>Hospice</b>	Nursing services, personal care , social services, physician visits, counseling, and homemaker services, pastoral care	Hospice team (physicians, nurses, social workers, clergy, volunteers)
		Licensed hospice facility or hospital

<sup>1</sup> Spouse cannot be paid to provide services under Medicaid

<sup>2</sup> Need a criminal background check and current first aid certification

<sup>3</sup> Must have current business license to provide the service

## TO FIND OUT ABOUT HOME HEALTH SERVICES

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- Contact your health plan first
- Locate a home health agency on the Utah Department of Health website: <http://health.utah.gov/hflcra>. Click on Facility Info, then Listing by County
- Call the Utah Association for Home Care at 801-466-7210 or go to [www.ua4hc.org](http://www.ua4hc.org)
- Call 211 statewide or go to [www.UCare.utah.gov](http://www.UCare.utah.gov)



If your family member is being treated for a medical condition, his or her health care provider is the first place to start. Your family member's doctor or health plan can recommend a home health agency. Your health plan may have a contract with a particular Home Health Agency and you are required to use that agency in order for the plan to pay. Medicare, Medicaid, and other health insurance plans may pay for home health services on a short term basis if your doctor states it is medically necessary.

The Medicaid Aging Waiver, Home and Community Based Alternatives program or The Utah Caregiver Support program may provide home health services on a longer term basis to prevent the person from having to go to a nursing home. Each of these programs has different rules for eligibility.

If you don't have insurance and can pay privately, contact a home health agency directly. They are listed in the yellow pages, or you can call the state Health Facility Licensing Bureau (800-662-4157) or <http://health.utah.gov/hflcra> to get a list of licensed home health agencies in your area. This website also has "report cards" for all health care facilities

licensed in the State of Utah. A report card lists complaints that have been investigated against that agency.

## WHERE TO FIND OUT ABOUT OTHER IN-HOME SERVICES

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The first place to start to learn more about finding in-home services is your local Area Agency on Aging (AAA).

- Contact your local Area Agency on Aging (877-424-4640) or [www.utahagingservices.org](http://www.utahagingservices.org)
- Call 211 statewide or go to [www.UCare.utah.gov](http://www.UCare.utah.gov)
- Call the Utah Association for Home Care at 801-466-7210 or go to [www.ua4hc.org](http://www.ua4hc.org)
- Utah Division of Services for People with Disabilities, Physical Disability Waiver program 800-837-6811 or visit <http://www.hsdspd.utah.gov>
- Alzheimer's Association
- Family Support Center

The first place to start to learn more about finding in-home services is your local Area Agency on Aging (AAA). These agencies are an excellent source of information about community programs, including personal care, homemaker and respite care. Whether you are able to pay for the service yourself, or are looking for financial assistance, the AAA has knowledgeable specialists who can provide information. The AAA administers several programs that provide funding for community supports for low income individuals for adults with disabilities as well as for seniors.

UCare supports an information and referral center that is comprehensive source of information about community services. You may contact UCare by phone or go to the website. The website has a very good search function.

To find out about hospice services in Utah, contact the End of Life Care Partnership at [www.carefordying.org](http://www.carefordying.org) or call (801) 892-0155.

## INFORMATION ABOUT ELIGIBILITY FOR PUBLIC PROGRAMS

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- See an eligibility specialist at the particular agency



This training is intended to provide general information about the kinds of services that are available to support a person in the community. We will not provide detailed information about eligibility for the different programs. That is the job for the eligibility specialists at the various agencies. This training prepares you to explain your needs and understand the kinds of services that are available to help you and your family member. See the list of agencies in the Resource section of the participant booklet.

Look at page 18 for the chart titled “Public Funding for Community Supports.” This chart lists the services down the left side column, and the public programs that provide community supports across the top. The dots show which services are covered by the different funding sources, including Medicare, Medicaid, the Medicaid Aging Waiver, the Home and Community Based Alternatives program and the Utah Caregiver Support program.

## MEDICARE

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- Medicare does not pay for long term care.

Medicare does not pay for long term care. You will notice on Chart C that Medicare only pays for home health services, medical equipment and supplies, and hospice. Medicare will only pay for a licensed health professional to provide home health service when it is determined to be medically necessary on a short term basis. Medicare will provide hospice services if the physician states the individual has less

than six months to live. Medicare does not provide long term in-home care or nursing home care.

## MEDICAID

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- Medicaid is for people who have low income and low assets.

If an individual has assets over the limit, they must use their resources to pay for their medical care until their assets are below the limit. The Medicaid program is different in every state, so be sure you get information about Utah Medicaid. You may apply for Medicaid at the Utah Department of Health or Department of Workforce Services offices. Or you may apply online at [www.utahclicks.org](http://www.utahclicks.org) (available in most areas). Call the Medicaid Information Line at 1-800-662-9651 for more information.

## THE MEDICAID AGING WAIVER

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- The Medicaid Aging Waiver allows persons to have greater income and assets than regular Medicaid.

The Medicaid Waiver program pays for in-home services if: 1) an individual qualifies for Medicaid and 2) would need to go in a nursing home if they didn't receive services in their home. The Medicaid Aging Waiver is different from regular Medicaid because if a person is eligible for a nursing home, the program allows them to have more income and assets, and exempts income from a spouse if they are living with the person. Eligible individuals receive all of the standard Medicaid benefits as well as the additional benefits of the Aging Waiver. Your local Area Agency on Aging (AAA) takes applications for the Medicaid Aging Waiver.



## THE HOME AND COMMUNITY BASED ALTERNATIVES PROGRAM

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- Persons must be at risk for a nursing home placement

To be eligible to participate in the program a person must: 1) be 18 years or older, 2) be at risk of nursing home placement, 3) have health and personal needs which can be adequately met in the community within established cost limits, and 4) have low income and minimal assets. Services are based on a care plan developed by a case manager.

Financial eligibility for the Alternatives Program is determined by the AAA case manager. Individuals who qualify for the program may be required to pay a small fee based on a sliding fee schedule. This state-funded program limits how much can be spent for each individual. Your local AAA takes applications for the Home and Community Based Alternatives program.

Notes:

## THE UTAH CAREGIVER SUPPORT PROGRAM

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- The Utah Caregiver Support Program provides information and support to caregivers

The Utah Caregiver Support Program provides information, assistance, support, caregiver training and counseling to: 1) caregivers of adults 60 years or older; 2) caregivers 60 years of age who are caring for persons with mental retardation and related developmental disabilities; and 3) grandparents or older individuals who are relative caregivers of a child younger than 18.

This program is a good resource for information about in-home supports for individuals who have resources to pay privately, but who need information about where to find providers, help with care planning, counseling, etc.

The program also provides respite and supplemental services to caregivers of adults over 60 who are unable to perform at least 2 activities of daily living. The program is funded through the federal Older Americans Act. For information and application, contact your local Area Agency on Aging (AAA).

## PRIVATE PAY

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Many individuals and families have resources to pay for in home supports but do not know where to get information. They may need assistance with care planning, counseling, and support to navigate the many private service providers, agencies and programs. Again, the AAA is a good place to start. The Utah Caregiver Support Program provides information and counseling to individuals regardless of their

ability to pay. Private care managers can also help plan, locate, and arrange services for a fee.

**Chart C: Public Funding for Community Supports**

	<b>Medicare</b>	<b>Medicaid</b>	<b>Medicaid Aging Waiver</b>	<b>Alternatives Program</b>	<b>Utah Caregiver Support Program</b>
<b>Home Health – Licensed Health Professional</b>	•	•			
<b>Home Health – CNA</b>	•	•	•	•	•
<b>Personal Attendant Service</b>		•	•	•	•
<b>Companion Service</b>			•	•	•
<b>Homemaker Service</b>			•	•	•
<b>Chore Service</b>			•	•	•
<b>Respite Care Service</b>			•	•	•
<b>Fiscal Management Service</b>			•	•	
<b>Trans- portation</b>		•	•	•	
<b>Medical equipment and supplies</b>	•	•	•	•	•
<b>Case Management</b>		•	•	•	•
<b>Adult Day Care</b>		•	•		•
<b>Individual Counseling</b>		•			•
<b>Support Group</b>		•			•
<b>Home Delivered Meals</b>			•	•	
<b>Hospice</b>	•	•			

## SUMMARY

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In this class you have learned about community supports that are available to help your family member to remain at home despite failing health or to return home after an illness or injury. You learned to use a checklist to identify tasks with which you need help. You learned some strategies for getting help with tasks on your checklist from friends or neighbors. And finally you learned about some public programs where you may be able to get services and funding to help pay for in-home and community support services.

## REMEMBER

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Remember that you don't have to do it all. It's okay to ask for help. There are community support programs that can help you.

Notes:

## Resources

### AREA AGENCIES ON AGING

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**Bear River AAA (BRAG)**

170 N. Main  
Logan, UT 84321  
(435) 752-7242  
(Box Elder, Cache and  
Rich Counties.)

**Davis County Council  
on Aging**

50 E. State Street  
Farmington, UT 84025  
(801) 451-3370

**Five County AAA**

1070 West 1600 South,  
Bldg. B  
St. George, UT 84770  
(435) 673-3548 or  
(435) 586-2975  
(Beaver, Garfield, Iron,  
Kane and Washington Counties)

**Mountainland AAA**

586 East 800 North  
Orem, UT 84097  
(801) 229-3800  
(Summit, Wasatch  
and Utah Counties)

**Salt Lake County  
Aging Services**

2001 S. State Street  
Salt Lake City, UT 84190  
(801) 468-2480

**San Juan County AAA**

117 S. Main Street  
Monticello, UT 84535  
(435) 587-3225

**Six County AAA**

250 N. Main Street, #5  
Richfield, UT 84701  
(435) 896-9222  
(Wayne, Piute, Juab, Sanpete,  
Millard,  
and Sevier Counties)

**Southeastern Utah AAA**

375 S. Carbon Avenue  
Price, UT 84501  
(435) 637-4268  
(Carbon, Emery and  
Grand Counties)

**Tooele AAA**

59 E. Vine Street  
Tooele, UT 84074  
(435) 882-2870

**Uintah Basin AAA**

330 East 100 South  
Roosevelt, UT 84066  
(435) 722-4518  
(Daggett and Duchesne  
Counties)

**Uintah County AAA**

155 South 100 West  
Vernal, UT 84078  
(435) 789-2169  
(Uintah County)

**Weber-Morgan AAA**

237 26th Street  
Ogden, UT 84401  
(801) 625-3770  
(Weber and Morgan  
Counties)

## MEDICARE

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Medicare Part A (Hospital Insurance) helps cover your inpatient care in hospitals, including critical access hospitals, and skilled nursing facilities (not custodial or long-term care). It also helps cover hospice care and some home health care. You must meet certain conditions to get these benefits. Cost: Most people don't have to pay a monthly payment, called a premium, for Part A. This is because they or a spouse paid Medicare taxes while working.

Medicare Part B (Medical Insurance) helps cover your doctors' services and outpatient care. It also covers some other medical services that Part A doesn't cover, such as some of the services of physical and occupational therapists, and some home health care. Part B helps pay for these covered services and supplies when they are medically necessary. Cost: You pay the Medicare Part B premium each month (\$88.50 per month in 2006). In some cases, this amount may be higher if you didn't sign up for Part B when you first became eligible.

Medicare Part D (Prescription drug coverage) helps cover your prescription drug costs. You must choose a plan to get this coverage. You pay a monthly premium. If you have limited income and resources, you may get Extra Help for paying the premium.

Medicare and You: 2006 is available at  
[www.medicare.gov/publications/pubs/pdf/10050.pdf](http://www.medicare.gov/publications/pubs/pdf/10050.pdf)

## MEDICAID

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Medicaid is health insurance that also covers community support services for certain groups of low income individuals with disabilities. The Medicaid program is different in every state, so be sure you get information about Utah Medicaid. You may apply for Medicaid at any Utah Department of Health or Department of Workforce Services office. Or you may apply online at [www.utahclicks.org](http://www.utahclicks.org) (available in most areas). Call the Medicaid Information Line at 1-800-662-9651 for more information or go to <http://hlunix.ex.state.ut.us/medicaid>.

## MEDICAID AGING WAIVER PROGRAM

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The Medicaid Aging Waiver Program provides services for people 65 and older who have medical problems to help them live outside of an institution. Eligibility is different from regular Medicaid because it allows special income deductions to meet their living expenses, exempts income from spouse even if they are living with them, and has a separate formula for calculation of assets. Individuals receive all of the standard Medicaid benefits as well as the additional benefits of the Aging Waiver. Medicaid will recover only the cost of actual care provided from the estate of the client. Medicaid does not take the entire estate.

To be eligible for the Medicaid Aging Waiver, an individual must be age 65 or older, a resident of the State of Utah and meet both financial and medical eligibility. A Case Manager works to develop a plan of care with the goal of assisting the individual to remain at home with services. The Case Manager assists with accessing community resources, authorizing use of Medicaid services, assuring quality of services provided and assuring that the health and safety needs of the individual are met in a home setting.

The Medicaid Aging Waiver is administered through the Utah Department of Health. The State Division of Aging and Adult Services is responsible for the daily operation of the program. There is a Case Management Agency for every area of the State of Utah. For further information contact your local Area Agency on Aging or the State Division of Aging at 1-801-538-3910 or go to [www.hsdaas.utah.gov/ss\\_in\\_home\\_services.htm](http://www.hsdaas.utah.gov/ss_in_home_services.htm)

## HOME AND COMMUNITY BASED ALTERNATIVES PROGRAM

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The Alternatives Program offers in-home services to enable individuals to remain in their own home for as long as possible. If these services were not available, these seniors who have health, mobility or functional limitations would not be able to continue living in their current living arrangements. The program offers a wide variety of in-home services available to adults based on an assessment of their needs.



The individual receives a comprehensive assessment by a case manager and, at times, a registered nurse, examining the client's physical, mental, social and financial status. The case manager works closely with the individual, their family, and other social and health agencies to identify service needs and the funding resources available to meet those needs.

The case manager develops and manages a comprehensive care plan of services designed to maintain the individual at home based on the assessment. Services are monitored monthly by the case manager to re-evaluate the individual's needs. [www.hsdaas.utah.gov/ss\\_in\\_home\\_services.htm](http://www.hsdaas.utah.gov/ss_in_home_services.htm)

## UTAH CAREGIVER SUPPORT PROGRAM

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The Utah Caregiver Support Program provides information, assistance, support, caregiver training, and counseling to: 1) caregivers of adults 60 years or older; 2) caregivers 60 years of age who are caring for persons with mental retardation and related developmental disabilities; and 2) grandparents or older individuals who are relative caregivers of a child not more than 18 years of age.

The Caregiver Support Program provides respite and supplemental services to caregivers of adults 60 years or older who are unable to perform at least two activities of daily living without substantial human assistance, including verbal reminding, physical cueing, or supervision.

Eligibility for respite and supplemental services is determined by using the Division of Aging and Adult Services approved assessment tool. For information on services and activities in your area, please contact your nearest Area Agency on Aging. [www.hsdaas.utah.gov/caregiver\\_support.htm](http://www.hsdaas.utah.gov/caregiver_support.htm)

## WEBSITES

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[www.ucare.utah.gov](http://www.ucare.utah.gov) –Within this site you should find answers to the following questions: What is long term care? How do I choose a long-term care option? What resources are available in Utah and nationally? What are some available

resources for Caregivers? Contact information for further assistance: email: [ucare@utah.gov](mailto:ucare@utah.gov) or call 211 or 1-888-826-9790 to speak with a specialist

[www.nfcacares.org](http://www.nfcacares.org) – The National Family Caregivers Association (NFCA) supports, empowers, educates, and speaks up for the more than 50 million Americans who care for a one. NFCA offers a newsletter, Tips, Guides, Education Pages, dealing with specific diseases, conditions and symptoms, Resources, and an educational program, Communicating Effectively with Healthcare Professionals.

[www.caregivers.com](http://www.caregivers.com) – Comprehensive website with a virtual caregiver support network, and detailed information on caregiving, health, drugs, products, books, housing, shopping, legal issues, insurance, and more.

[www.Eldercare.gov](http://www.Eldercare.gov) - The Eldercare Locator is a public service of the U.S. Administration on Aging. The Eldercare Locator connects older Americans and their caregivers with sources of information on senior services. The service links those who need assistance with state and local area agencies on aging and community-based organizations that serve older adults and their caregivers. You may find the information resources you need at the website or speak to an Eldercare Locator information specialist by calling 1-800-677-1116.

[www.eldercarelink.com](http://www.eldercarelink.com) - ElderCarelink is an internet-based referral service—free to consumers—that specializes in eldercare case matching for elders and their families. ElderCarelink assists families in finding a multitude of services, including assisted living, nursing homes, adult day care, private duty nursing, care management and homecare. With participating providers in all 50 states, ElderCarelink identifies qualified eldercare service providers and product suppliers who meet the specific needs for each family's individual situation. ElderCarelink helps families identify the right type of care and services needed, highlighting both medical and lifestyle needs, as well as budget and financing options. The names of the matched providers are sent via e-mail to the requesting individual, while the requesting individual's name and profiling

information are passed along to the matched provider(s). These providers are pre-approved through an authorization on the profile submission to contact the requesting individual to pursue further discussions.

[www.strengthforcaring.com](http://www.strengthforcaring.com) - A comprehensive online resource and community for family caregivers. The site includes caregiving resources including articles devoted to caregivers' health, emotional, and personal needs, message boards provide 24/7 support where caregivers can tell their personal stories and receive help and tips from other caregivers about the issues they face and a monthly newsletter.

[www.aarp.org/families/caregiving](http://www.aarp.org/families/caregiving) - Offers expert advice and resources on caregiving, guardianship, health professionals, long distance caregiving, assessing your parents, long term care ombudsman, balancing work and caregiving, community resources, hiring a home health worker, and much more.

[www.caregiver.org](http://www.caregiver.org) – The Family Caregiver Alliance (FCA) offers programs at national, state and local levels to support and sustain caregivers. FCA offers online discussion groups, fact sheets, handbook for long-distance caregivers, local resources, newsletter, tips, policy digest, research, and more.

[www.aoa.gov](http://www.aoa.gov) or <http://www.aoa.gov/prof/aoaprogram/caregiver/caregiver.asp> - The National Family Caregiver Support Program (NFCSP) was developed by the Administration on Aging (AoA), U.S. Department of Health and Human Services. The Caregiver Resource Room is where families, caregivers, and professionals can find information about where you can turn for support and assistance and available services for caregivers. Numerous fact sheets are available.

[www.caremanager.org](http://www.caremanager.org) - This Web site can help you locate a geriatric care manager who can oversee your parents' care. A geriatric care manager is a health and human services professional, such as a gerontologist, nurse, social worker, or psychologist with a specialized focus on aging and elder care. Geriatric care managers work privately with older adults and their families to create a plan of

care. They will help you understand your loved one's needs and to learn what resources and options are available to meet those needs. The National Association of Professional Geriatric Care Managers (GCM) is a non-profit association of professional practitioners whose purpose is the development, advancement, and promotion of humane and dignified social, psychological, and health care for the elderly and their families through counseling, treatment, and services by qualified, certified providers.

[www.respitelocator.org](http://www.respitelocator.org) - The National Respite Locator Service helps parents, caregivers, and professionals find respite services in their state and local area to match their specific needs.

## GLOSSARY

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**Activities of Daily Living** – Personal care activities necessary for everyday living, such as eating, bathing, grooming, dressing, and toileting; a term often used by healthcare professionals to assess the need and/or type of care a person may require.

**Adult Day Services** – Provide a supervised setting in which health and social services are provided on an intermittent basis to ensure the optimal functioning of the participant. Adult day services are generally 4 or more hours per day on regularly scheduled basis, for one or more days per week or as specified in the care plan. Transportation may be provided. (See Transportation)

**Chore Services** – Perform heavy household chores, such as washing floors, windows, walls, tacking down loose rugs, and tiles, moving heavy items of furniture to provide safe entry and exit. In case of rental property the responsibility of a landlord in a lease agreement will be examined.

**Companion Services** – Provide non-medical care, supervision and socialization of an individual. Companions may assist or supervise the individual with such tasks as meal preparation, laundry and shopping, but do not perform these activities as discrete services. Companions may also perform light housekeeping which are incidental to the care and supervision of the individual.

**Fiscal Management Services** – An agency that facilitates employment of personal attendants by performing three functions: 1) verifying provider qualifications, such as conducting a criminal background check; 2) performing payroll functions, such as issuing paychecks and filing federal, state and local tax withholding payments, unemployment tax, etc. and 3) processing Medicaid claims for reimbursement.

**Home Health Services** – Nursing, or personal care or other services provided in the home by a licensed health professional, such as a registered nurse (RN), or certified nursing assistant (CNA), or other health professional. Services must be ordered by a physician and must be medically necessary to maintain or improve a health condition.

**Homemaker Services** – General household activities, including meal preparation and routine household care provided by a trained homemaker, when the individual regularly responsible for those activities is temporarily absent or unable to manage the home and care for him or herself or others in the home.

**Instrumental Activities of Daily Living (IADL)** – More complex activities, not necessarily done everyday, but which are important to independent living. Examples include preparing meals, doing housework, doing laundry, using transportation, shopping, managing money, using the telephone, and doing home maintenance.

**Participant-Directed Personal Attendant Services** – The participant (service recipient) is the employer of the personal attendant provider. This means that the participant has control over the selection, retention and supervision of the personal attendant and verification of the personal attendant's time sheet. Participant-directed personal attendant services require the use of a Fiscal Management Service. (see definition)

**Personal Attendant Services** (also referred to as Personal Care, Personal Assistance or PAS) – provide physical or cognitive assistance with eating, bathing, dressing, personal hygiene, and other activities of daily living (ADLs) to a medically stable person. PAS may also include help with meal preparation, homemaker services, chore services, and other instrumental activities of daily living (IADLs) incidental to personal care. PAS is provided on a regularly scheduled basis.

**Personal Emergency Response System** – An electronic device that allows an individual to summon assistance in an emergency. The device is connected to a signal response center which is staffed 24-hours a day, 7 days a week by trained professionals responsible for dispatching assistance in the event of an emergency.

**Respite Care Services** – Care, supervision or companionship provided by an attendant, companion, homemaker, home health aide, etc. which is provided during the absence of, or to relieve the normal caregiver. Respite care services are not restricted to the individual's home.

**Spenddown** – refers to the amount of medical expenses that are a person's financial responsibility, similar to an insurance deductible. The spenddown amount is the amount by which an individual's or couple's net income exceeds the non-spenddown income limit. A person's spenddown obligation can be met by either: 1) submitting incurred medical expenses to their caseworker on a monthly basis; or 2) paying the monthly spenddown amount to the Medicaid office, much like an insurance premium payment.

**Supplemental services** – Services that are provided by the Utah Caregiver Support Program if another funding source has been exhausted (used up). Supplemental services are available on a limited basis to complement care provided by caregivers.

**Transportation (medical)** – Transporting individuals to medical appointments for non-emergency and emergency reasons.

**Transportation (non-medical)** – Transporting an eligible individual between home and community services, activities and resources specified in the service plan. Non-medical transportation must be specified in the service plan.